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ABSTRACT

A diagnosis of Acquired Immune Deficiency Syndrome (AIDS) has both a physical and psychosocial impact that require substantial support. Relating to the families of origin concerning an AIDS diagnosis is a difficult task which sometimes results in rejection and sometimes results in support. In this study subjects (N=32) with AIDS described their experiences of relating to their families of origin about the AIDS diagnosis. Subjects were asked to respond to questions concerning changes that occurred in their lives because of the AIDS diagnosis, their perceptions of their families' support, and their families' knowledge of their homosexual lifestyle. They also completed measures of family functioning, affective responsiveness, loneliness, and anxiety. Most subjects indicated that there had been at least some change in their support networks. Most parents were aware of the diagnosis. One-half of the subjects reported that the knowledge of their illness had affected family functioning. Most parents knew of the subjects' homosexual lifestyle. Nearly one-half of the subjects perceived their families as healthy. Subjects reported moderate loneliness and low to moderate anxiety. Since support is so critical, helping professionals could facilitate family support and a balance between support and denial as important interventions. (Author/ABL)

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AIDS: A Strain on Family Relations

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Abstract

A diagnosis of AIDS has both a physical and psychosocial impact that requires substantial support. Relating to the families of origin concerning an AIDS diagnosis is a difficult task which sometimes results in rejection and sometimes results in support. In this study 32 people with AIDS describe their experiences of relating to their families of origin about the AIDS diagnosis.

Key Words: AIDS, Family

Life changes when a person is diagnosed with AIDS. It is a catastrophic illness with a traumatic impact which challenges the coping abilities of those who have the disease and of the families who must respond to its implications. In addition to those issues and concerns that might be expected when a family member has a life-threatening illness, there are additional burdens for the people who have AIDS (PWAs) and for their families. Because AIDS is a disease that is associated with stigma and fear, PWAs and their families are often faced with hostility and ostracism rather than support.

In the growing body of literature regarding AIDS, it is often reported that the response of the families of PWAs parallels society's responses and many of these families withdraw their support when they learn about the AIDS diagnosis (Blaney & Piccola, 1987; Geary, 1987; Carl, 1986; Furstenberg & Olsen, 1984). The withdrawal of support is critical to the PWA because of the trauma of the decompensating physical condition, the many losses incurred, the high cost of medical care, and the emotional responses to the disease process. People with AIDS are reported to experience the loss of friends, family support, jobs, and consequently medical insurance and their homes. Their emotional responses to this disease and its implications include anxiety, depression, isolation, feelings of immobilization and loss of control, self-rejection and blame (Blaney & Piccola, 1987; Cleveland, 1987; Carl, 1986; Dilly, 1985; Furstenberg & Olsen, 1984; Morin & Batchelor, 1984).

The great needs of the PWAs indicate that family support is very important. In the studies of family crises, findings have provided information that has added to our understanding of how crises affect family functioning and how families cope with some catastrophic illnesses. However, not much is known about how PWAs and their families relate around the issues of AIDS.

In this study 32 people with AIDS were asked to respond to questions concerning changes that occurred in their lives because of the AIDS diagnosis, their perceptions of their families' support, and their families' knowledge of their gay life style. In addition, they completed two dimensions of the McMaster Family Assessment device, the revised UCLA Loneliness, Scale and the State-Trait Anxiety Inventory. The open-ended questions have been analyzed to determine whether there is a pattern in the responses, and the relation between significant variables i.e., anxiety, loneliness, and family support, has been examined.

Method

Subjects

All were receiving services from AID Atlanta. All of the clients in this sample had been diagnosed with AIDS within six months to three years prior to the time of the study.

In this sample of people with AIDS there were 29 white and 3 black patients; 30 were male and 2 were female. The ages ranged from 24-49. For 15 of these patients where they live represents

a change of habitat within the last six months. Ten of the participants explained that the change in living arrangement was directly related to the medical diagnosis. Five said that lovers or roommates left after their disclosure of the diagnosis. Five other patients moved to a smaller place or to be with someone else because of increasing physical weakness or financial difficulties. Currently 13 of the patients live alone and 15 live with someone else besides a partner. Only four are with partners.

Procedure

Leaders of support groups for PWAs distributed the questionnaires to those who were interested in participating in the study. Participation was voluntary and no records were kept that would indicate any identification of those who participated.

Instrumentation

The McMaster Family Assessment Device (FAD)

Designed to measure family functioning, the FAD is made up of seven scales, one measuring overall functioning and one for each of the six dimensions of the McMaster model, e.g., problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control. Scale scores have a possible range of 1.00 (healthy) to 4.00 (unhealthy). Because these subjects were adults and were living away from the families of origin, only two dimensions of the scale were used i.e., Affective Responses and Affective Involvement.

Affective responsiveness is defined as the ability to respond to a given stimulus with the appropriate quality and quantity of feelings. Affective Involvement is the extent to which the family shows interest in and values the particular activities and interest of individual family members. This includes the amount of interest the family demonstrates as well as the manner in which the family members show interest in and invest themselves in one another (Epstein, Bishop, Baldwin, 1982).

Respondents were asked to indicate the degree to which statements described their family of origin. Examples of these statements are: "When someone is upset, others know why"; "In times of crises, we can turn to each other"; "Individuals are accepted for what they are"; "We cannot talk to each other about the sadness we feel" (Epstein, Baldwin, Bishop, 1982). Using Cronback's alpha, reliability was estimated to be .94. (See Table 2.)

The Revised UCLA Loneliness Scale

This scale is a 20-item self report measure developed by Russell, Peplau, and Cutrona which is based on an earlier scale developed by Russel, Peplau, and Ferguson in 1978 (Russell, Peplau, Cutrona, 1980). The scale requires respondents to rate their loneliness on a 7-point scale ranging from 1 (never) to 7 (often). The range of scores is 20 to 70 with 20 indicating the least loneliness. An Alpha of .95 was estimated for this scale (See Table 3).

The State-Trait Anxiety Inventory (STAI)

This instrument includes separate self-report scales for measuring two distinct anxiety concepts: State anxiety (A-State) and trait anxiety (A-Trait). Both scales consist of 20 questions. The A-State scale is a measure of how respondents feel at the particular time of questioning, including transitory emotional state or condition. The A-Trait scale is a measure of general feelings that are relatively stable indicators of anxiety proneness (Spielberger, Gorsach, and Lushene, 1977). Individuals respond to each STAI item by rating themselves on a four-point scale. The range of scores is 20-80 with 20 indicating the least anxiety. Alphas of .97 and .94 were estimated for SAI and TAI respectively. (See Table 4)

RESULTS

The following are open-ended questions and the responses of the participants. Examples of responses are reported to gain perspective on the experiences of the people with AIDS.

Support Network

In response to the question: "Has your support network changed as a result of your medical diagnosis?"; twenty-five (78%) of the respondents answered that their network had changed because of the medical diagnosis. Eleven (34%) described the change as "drastic;" twelve (38%) said there had been some change; two (.06%) had experienced very little change. Some described being left by lovers, friends, employers, and family members. Others explained that families who were once

estranged had become close, and some said that groups of friends had become available because of their illness and were very important. Statements such as the following are examples of the kinds of changes the PWAs experienced:

"I lost some old friends and found some new ones."

"My parents have grown closer. They promised to stand by me."

"My lover left me, my family turned away from me-- Mother, Father, brothers, aunts, uncles - all are afraid of the disease."

"There has been a decline in the reliability of my family."

"My relationships with my lover, my siblings, my parents, my grandparents and my friends in general have been enhanced and have grown deeper and more meaningful."

"My family is too involved in their own grief and fear and disbelief. They either deny the problem and don't deal with it, or try to give me a false sense of hope. But they do care."

"Several people have closed themselves off, but a few people have become closer."

"Support network has been strengthened due to my association with others in support group."

Awareness of Medical Diagnosis

In response to the question: "Are your parents aware of your medical diagnosis?" twenty-six (81%) indicated that their parents were aware of their medical diagnosis. Spouses of the patients who were married knew of the diagnosis. Almost 90% (21) of the AIDS patients learned about their diagnosis 2-12 months prior to the time of the study and those

who had disclosed the diagnosis to their parents did so soon after they learned.

Twenty-five (78%) of the participants described their parents' reactions to the news of their diagnosis. Only four of these described painful rejection and total lack of support. The remainder (21) discovered support which came after an initial period of shock but had continued and sustained them. The following statements are examples of responses as perceived by PWAs.

"My mother is hearbroken but supportive. My father can't face the facts."

"Accepting and upset at the same time."

"I think my Mother is falling apart inside and she never discusses it."

"They are scared of the disease - afraid of getting it from me."

"Denial, rejection, anger, that I got what I deserved."

"Shocked, angry, but supportive after awhile."

Even though anger was reported to be a response of parents, sadness was the most often reported affect.

Twenty-eight also reported that other people in their families also were aware of the diagnosis, including siblings, cousins and grandparents. Seven (2%) described total rejection citing fear of the disease and abhorrence of the participants' homosexuality as the reasons for their inability to be supportive. Most (69%) described some support which varied from, "They worry about me;" "They are concerned

about me;" and "They are great."

Effect of Present Medical Situation on Families

When asked "Do you believe that your family's knowledge of your present medical situation has affected your family's functioning?" one half of the respondents answered "yes" and one-half answered "no," but only 12 of the participants attempted to describe the ways in which the families had been affected. The following are examples of responses:

"We talk more than we ever did."

"The family does not gather at Christmas like they used to."

"My Mother acts fearful that I'll overwork myself and weaken. She wants to baby me, but I don't allow it. I'm more in charge in certain matters so their reactions don't get out of hand."

"We are no longer a family."

"Making every moment count."

"My father had to give up some of his civic obligations and one of my sisters has caused some stress on the family by her occasional homophobia."

"They check in more often. My father and I are much closer now."

The respondents who reported that family functioning had been positively affected, stated that there had been an increase in communication in the family. Negative results, e.g. total rejection or open conflict, were attributed to families' inability to accept the gay lifestyle.

Knowledge of Homosexuality

"Do your parents know that you are gay or bisexual?" was

the last question to which the participants responded. Twenty-two (68%) responded "yes," and about one half disclosed this lifestyle after they disclosed the diagnosis of AIDS. Parents' reactions were described as follows:

"Like many, they can't accept my lifestyle, but they'll go to any length to help me."

"We never discussed it."

"Supportive, were concerned about whether I'd be happy with my lifestyle."

"Upset but ultimately tolerating."

"My family despises my being gay."

The patterns in these responses confirmed that parents go through a process of acceptance. Most of the respondents stated that those parents who knew about their sexual orientation really never completely understood or accepted it. Those parents who didn't know until they knew about the AIDS diagnosis were described as confused, sad, or overwhelmed.

Adequacy of Support

Participants were asked to rate the adequacy of support that was given to them by significant people in their lives. One half rated the support of their families as "very adequate," three, as "somewhat adequate," and two as "adequate." The most often mentioned supportive relationships were with mother, sister, and father, in that order. Although the majority perceived their families as supportive, fewer lived within 30 miles of an adult member of their family.

The kind of support that was given ranged from expressions

of concern to financial help. Some reported that parents checked in with them more often and sent cards or presents. Only one said that his family would like to be supportive but he would not allow it because of earlier rejection related to his sexual orientation.

Family Assessment

Fourteen (45%) of the PWAs perceived their families as healthy with a greater percentage (32%) perceiving their families as very healthy than the number who viewed their families as unhealthy (20.6%). Families were perceived as using a wide range of affective responses that are appropriate in amount and quality to the stimulus and to being empathic in their involvement with these participants. Table 1 contains the delineation of scores on this scale.

Table 1

FAMILY ASSESSMENT

SCORES	<u>n</u>	<u>%</u>
1.0-2.0	10	32.3
2.1-3.0	14	45.2
3.1-4.0	7	22.6

M = 2.24

SD = .67

Loneliness

The mean score on the loneliness scale indicates only moderate loneliness for this sample with some reporting high levels of loneliness. When the relation of loneliness to other

variables was examined, it was found to be important. Loneliness was found to be significantly correlated to perception of support in general ($r = -.50$ $p < .05$); to state anxiety $r = .68$ $p < .05$) and to perceived affective responses/involvement with the family of origin ($r = .48$ $p < .05$). These indicate that a decrease in support is associated with an increase in loneliness. Apparently those who perceived support were less lonely; those who were lonely were more anxious; and those who perceived their families as being involved with them were less lonely. Table 2 contains the scores on this scale.

Table 2
LONELINESS

SCORES	<u>n</u>	<u>%</u>
20-30	6	19.4
31-40	7	22.6
41-50	11	35.5
51-60	5	16.1
61-70	2	6.5
<u>M</u> = 41.45		
<u>SD</u> = 12.7		

Anxiety

The scores on the state and trait anxiety scales reflect low to moderate levels of anxiety. There was a significant correlation between trait anxiety and state anxiety in this sample ($t = .78$). The anxiety scores were lower than expected based on the literature. This may be due to several factors

(a) anxiety may be buffered by some mediating factor such as support, (b) there is a lack of self awareness that enables those in this sample to identify these feelings, or (c) predictable denial, which is a part of this disease process, is operating. Tables 3 and 4 contain the scores for these scales.

Table 3
STATE ANXIETY

SCORES	<u>n</u>	<u>%</u>
20-30	3	10.0
31-40	8	26.7
41-50	9	30.0
51-60	8	26.7
61-70	0	
71-80	2	6.67

M = 44.6
SD = 13.40

Table 4
TRAIT ANXIETY

SCORES	<u>n</u>	<u>%</u>
20-30	4	12.5
31-40	4	12.5
41-50	18	58.1
51-60	4	12.9
61-70	1	3.2
71-80	1	

M = 43.2
SD = 9.27

The findings in this study to some degree support the information we have received in other reports, specifically that the AIDS diagnosis has a traumatic impact on the PWA and on the family of that person. In this study the perceived support of families of origin made a difference to the psychological responses of PWAs. Those who perceived support were less lonely and less anxious.

The kinds of support provided by family members include emotional support primarily, and for many, financial and other kinds of tangible aid. Some PWAs reported that they thought that the families' support may include caring for them physically and financially when they are unable to do so for themselves. However, most of the participants did not discuss this.

The issue of homosexuality was important in this sample. Those PWAs who experienced total rejection found that this rejection was due mostly to the lack of acceptance of their gay life style. The fear of contagion was mentioned by only a few respondents and was cited as the sole reason for rejection by only one person. Those who were heterosexual did not experience the rejection by family members that was so much a part of the experience of the homosexual respondents.

Many of the respondents who reported that their parents and others in their families know about their gay lifestyle indicated that these family members had experienced a time of adjustment to the disclosure. Some parents were able to be

supportive even though they felt angry and hurt; others were supportive after an initial period of time when they were unsupportive.

The issue of denial is interesting. Most of these participants indicated that their mental health was good and that their level of stress was medium to very low. The degree of anxiety and loneliness are lower than might be expected given the seriousness of the illness. It seems unlikely that the level of stress and the degree of anxiety and loneliness can be low unless some denial is operating. Denial has been identified as fairly typical at the beginning of the AIDS process followed by a reaction which is characterized by crisis, disorganized thinking, and depression (Nichols, 1985; Wein, 1983).

Implications for Helping Professions

Since support is so critical, a major intervention is facilitating that support. Clinicians at AID Atlanta have reported that many PWAs are reluctant to contact their families to disclose their diagnosis for fear of rejection (Geary, 1987). One of the first functions is to support and enable them in facing the need to disclose their diagnosis to their families and to prepare them for the contact.

It is a reasonable expectation that when families of homosexual men diagnosed with AIDS have prior knowledge of their lifestyle and have already reached some degree of acceptance of it, it is easier for families and patients to face the problems of the illness, such as physical care and financial need. How-

ever when families do not know their children are gay until they learn they have AIDS, we might expect that they must go through a process of acceptance of the lifestyle before they can face the acceptance of losing their child. This process is very hurtful to the PWA and is the most common cause of estrangement. So, another major task is mediating and facilitating these parallel processes of grief in the child and in the family. One of the major components of the acceptance of the gay lifestyle is the understanding and respect for the role of the partner of the gay person. This is reported to be a difficult task for most families (Blaney & Piccola, 1987; Geary, 1987; Carl, 1986; Furstenberg & Olsen, 1984).

Taking care of unfinished business allows constructive grief work and preparation for the death of a loved person. In a study of reactions to the death of adult children who died of cancer, emotional closeness and the amount of communication between the parent and child during the illness were associated with aspects of the bereavement outcome. The parents who had felt closest to the ill children tended to report that the loss of the child was the worst loss they have ever experienced. They also reported less guilt and had less unfinished business with their children at the time of death (Shunfield, Benjamin, Swain, 1984). So both the children and their parents need to settle the issues that are barriers between them.

Another major task is to facilitate the families' ability to achieve the balance between denial and acceptance. Some

denial appears to be necessary in order to give hope, but acceptance is necessary in order to solve the problems that are presented by a terminal illness.

Clearly the diagnosis of AIDS, with the attendant implications presents a crisis to any family. The task for those who work with these families is to have the vision, the patience, and the courage to grapple with our own inner feelings regarding the myriad implications of this disease in order to be more able to help client families find, in the face of overwhelming tragedy, a new equilibrium that enables life to go on in the face of that tragedy.

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